ACC.11
60th Annual Scientific Session & Expo

E465
JACC April 5, 2011
Volume 57, Issue 14

CONGENITAL CARDIOLOGY SOLUTIONS (ADULT CONGENITAL AND PEDIATRIC CARDIOLOGY)

ADOLESCENTS TRANSITIONING FROM PEDIATRIC TO ADULT CONGENITAL CARDIAC CARE: ARE THEY EDUCATED ABOUT THEIR DISEASE AND POTENTIAL RISKS?

ACC Poster Contributions
Ernest N. Morial Convention Center, Hall F
Monday, April 04, 2011, 3:30 p.m.-4:45 p.m.

Session Title: Adult Congenital Heart Disease
Abstract Category: 43. Adult Congenital Heart Disease
Session-Poster Board Number: 1133-434

Authors: *Jenne K. Hickey, Laura Schmidt, Angela Woods, Curt Daniels, Nationwide Children's Hospital, Columbus, OH*

Background: Previous studies have demonstrated the majority of congenital heart disease (CHD) patients (pts) are lost to care transitioning from pediatric to ACHD. This may contribute to early morbidity and mortality. A number of factors have been implicated including lack of available specialized care and loss of insurance. To date, no US study has specifically evaluated the knowledge base of an unbiased adolescent and young CHD population in pediatric cardiology (PC) care. Therefore, we sought to determine whether adolescent and young adult CHD pts are educated regarding their CHD diagnosis, risks, and need for follow up while in PC prior to transitioning to ACHD care and potentially lost.

Methods: All pts > 15 yrs of age with CHD presenting to their PC for routine care between 9/08 -9/10 were surveyed. Questions included: biographical, adult lifestyle issues, knowledge of cardiac lesion, and need for lifelong care. Pts' description of their cardiac lesion were measured as correct, or incorrect according to chart diagnosis. Pts were divided into early, mid, and late based upon the time frame surveyed, evaluating trends. Survey answers compared by t -test and Chi-Square analysis. Significance $p < 0.05$.

Results: Over the past 25 months, 226 pts, age 15-39 (mean 20.2 ± 4.3yrs) completed the survey. The majority of pts (>50%) reported they received education regarding diet, exercise, and antibiotic prophylaxis. However, 51% did not know their CHD diagnosis, $p < 0.001$, 22% reported their heart disease was cured, and 33% did not know they required cardiology care as adults. Also, 81% of the women had not received information or discussed birth control and 76 % pregnancy risk, $p < 0.001$. From the early to late period, we found differences regarding knowledge of diagnosis, need for follow up care or education regarding birth control/pregnancy.

Conclusions: In a survey of adolescent and young adult CHD pts in a single center PC practice, we found a significant number of pts did not know their diagnosis, and reported their CHD was cured and therefore did not require long-term cardiology follow-up. A national initiative focusing on transition education is necessary to improve the care of CHD pts.